

Impact of Health Literacy on Longitudinal Asthma Outcomes

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BACKGROUND: The impact of health literacy on longitudinal asthma outcomes is not known.

OBJECTIVES: To measure the association between health literacy and asthma outcomes and to assess how health literacy affects outcomes through covariates.

DESIGN: Longitudinal cohort.

PATIENTS: One hundred and seventy-five adult asthma patients.

MEASUREMENTS: Independent variables measured at enrollment included demographic and asthma characteristics, depressive symptoms, self-efficacy, and asthma knowledge. Health literacy was measured with the Test of Functional Health Literacy in Adults. Outcomes were Asthma Quality of Life Questionnaire and SF-36 scores and emergency department utilization for asthma measured every 3 to 6 months for 2 years. The effects of health literacy on outcomes and interactions between health literacy and covariates were measured with multivariable models.

RESULTS: The mean age of study participants was 42 years, and 83% were women. Less health literacy was associated with worse quality of life, worse physical function, and more emergency department utilization for asthma over 2 years ($P \leq .05$ for all comparisons). In multivariable analysis, health literacy did not remain statistically significant with any of the outcomes. Although the magnitude of its effect on emergency department utilization remained relatively intact, its effects on quality of life and functional status became attenuated with the sequential addition of covariates, particularly asthma knowledge.

CONCLUSIONS: Less health literacy was associated with poor longitudinal asthma outcomes. This relationship was both direct and indirect through effects on other independent variables, particularly patients' knowledge of asthma and self-management. Efforts to improve asthma outcomes should focus on improving literacy skills that are required to learn, understand, and implement effective self-management.

KEY WORDS: health literacy; asthma; quality of life; outcomes; emergency department utilization.

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The term health literacy has been used to describe the ability to read and comprehend medical information.¹ Such skills may impact all aspects of medical care. In particular, multiple studies carried out in different countries provide evidence that patients with less health literacy have worse health outcomes.^{2,3} Some of the main outcomes considered were resource utilization and markers of disease control.^{4,5}

In addition, it is possible that health literacy may not only act directly on outcomes, but also may exert its effects through other variables. Thus, the true impact of health literacy may not be appreciated unless a detailed analysis of its effects on other known determinants of outcome is carried out. For example, for patients with asthma, inadequate health literacy

may prevent acquisition of asthma knowledge and self-efficacy, and may lead to less effective asthma self-management.^{6,7} All these variables are well-known determinants of long-term asthma outcomes^{8,9} and the possible impact of health literacy on these variables is not known.

The goals of this analysis were to measure the association between health literacy and longitudinal outcomes in a cohort of asthma patients, and to assess the relationship between health literacy and other variables that are independently related to outcomes.

METHODS

Participants

The 175 patients in this analysis were derived from a cohort of 224 adult patients who were enrolled in an observational study from 1995 to 1999.⁸ Patients were eligible for the larger study if they required daily asthma medications, such as inhaled corticosteroids. Patients were enrolled when they came for scheduled office visits with their physicians at the Cornell Internal Medicine Associates, a primary care practice serving patients of diverse socioeconomic groups from all areas of New York City. The goals of the larger study were to identify independent variables associated with asthma outcomes over 2 years, such as demographic and asthma characteristics, self-efficacy, depressive symptoms, and types of medications. Outcomes of interest were quality of life, functional status, and urgent resource utilization. At enrollment, patients completed a battery of questionnaires (described below) during an in-person interview in either English or Spanish. Patients then had follow-ups every 3 to 6 months either in person when they came for office visits with their physicians or by telephone if they did not come for repeat visits during the study period. One hundred and seventy-five patients who had in-person follow-ups also completed the Test of Functional Health Literacy in Adults (TOFHLA)¹⁰ (described below) during one of these follow-ups and were included in the current analysis. The TOFHLA was added to the protocol because during the initial phase of enrollment, it became apparent that some patients had difficulty reading the questionnaires and preferred to be interviewed. Thus, we decided to measure health literacy formally as part of this study.

Definitions of outcome and characteristics of independent variables have been described elsewhere and are briefly summarized here.⁸

Outcomes

The main outcome was the pattern of overall asthma-related quality of life measured with the Asthma Quality of Life Questionnaire (AQLQ) at enrollment and approximately every 6 months for 2 years. The AQLQ is a 32-item well-established scale measuring symptoms, activity limitations, and the effects of emotions and the environment on asthma.¹¹

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Functional status was measured with the Medical Outcomes Study SF-36, composed of Physical and Mental Component Summary scores.¹² The SF-36 was also administered at enrollment and every 6 months. Resource utilization for asthma, particularly emergency department visits, was measured by self-report every 3 months by telephone or in person during office visits.

Independent Variables

Variables possibly associated with outcomes were measured at enrollment. In addition to demographic questions, patients were asked about access to asthma care, rated from "very difficult" to "very easy." Information about medications was obtained, and requiring daily oral beta agonists was considered a proxy for more severe disease. Patients also completed the Asthma Self-efficacy Scale, an 80-item scale measuring confidence in self-managing asthma when confronted with precipitants.¹³ Knowledge of asthma was measured with the Check Your Asthma IQ, a 12-item survey measuring awareness of asthma characteristics, mechanisms, and self-management.¹⁴ Patients were also asked about the use of a peak flow meter. Other generic variables associated with asthma outcomes were also assessed, such as depressive symptoms, which was measured with the Geriatric Depression Scale (GDS).¹⁵ The GDS is a well-established 30-item scale that has been shown to be valid in younger patients.¹⁶ The GDS was chosen for this study because it measures psychological, as opposed to somatic, symptoms.

As indicated above, the TOFHLA was administered in person to those patients who returned for a physician office visit. Either the English or Spanish version was administered according to patient preference. The TOFHLA is a widely used 67-item instrument measuring literacy and numeracy skills applicable to health care situations. A composite score can be calculated for both domains (collectively referred to here as "health literacy"), ranging from 0 to 100, with higher scores indicating greater skills. Although the TOFHLA generates a continuous score, the clinical impact of health literacy probably is not continuous. Instead, it is likely that there is a certain threshold of competence that is required for a patient to function effectively in a health care setting. As part of the testing phase, the authors of the TOFHLA defined a score of ≥ 75 as adequate health literacy, a score of 60 to 74 as marginal, and a score of <60 as inadequate health literacy.¹⁷

Data Analysis

Bivariate associations were carried out with *t* tests, analysis of variance, and χ^2 tests. Health literacy was dichotomized as "adequate" or "marginal/inadequate" according to the above criteria. Spearman's correlations were calculated for health literacy and covariates, specifically self-efficacy, depressive symptoms, and knowledge. Mixed-effect models with a random subject effect were used for analysis of outcomes that were continuous, specifically patterns of repeatedly collected quality of life (AQLQ) and functional status (SF-36) scores. Sequential models were set up with AQLQ (or SF-36) scores as the dependent variable. Independent variables that were significant with $P \leq .05$ in bivariate analyses were entered into the models in a forward stepwise fashion, starting with health literacy. These analyses were carried out using PROC MIXED

in SAS.¹⁸ Similar analyses were carried out for the resource utilization outcome, which was dichotomized as having or not having had an emergency department visit for asthma during the study period, using PROC GENMOD in SAS. All analyses were controlled for time in the study.

This study was approved by the Committee on Human Rights in Research at the Weill Medical College of Cornell University.

RESULTS

Of the 224 patients enrolled in the larger study, 175 patients came for in-person follow-ups and completed the TOFHLA. These 175 did not differ from the 49 patients who did not complete the TOFHLA with respect to sex, education, income, duration of asthma, prior hospitalizations, and scores on the quality of life, functional status, self-efficacy, depressive symptoms, and asthma knowledge questionnaires. However, those who completed the TOFHLA were older than those who did not (42 vs 37 years old, $P=.0006$). Demographic and asthma characteristics for the 175 patients included in this analysis are shown in Table 1.

Of these 175 patients, 143 (82%) had adequate health literacy (TOFHLA ≥ 75), 14 (8%) had marginal health literacy (TOFHLA 60 to 74), and 18 (10%) had inadequate health literacy (TOFHLA <60). In subsequent analyses, the sample was dichotomized into those with adequate health literacy (82%) and those with marginal/inadequate health literacy (18%).

In bivariate analysis controlling for duration of follow-up, there was a statistically significant association between less health literacy and worse quality of life (AQLQ) ($P=.009$), worse physical function (PCS) ($P=.0007$), and having been treated in the emergency department for asthma during the study period ($P=.03$) (Table 2). The association between health

Table 1. Patient and Asthma Characteristics

	All Patients (N=175)	Literacy Level		P Value
		Adequate (n=143)	Marginal/ Inadequate (n=32)	
Age, years (mean \pm SD)	42 \pm 10	41 \pm 10	50 \pm 8	<.0001
Women	83%	83%	84%	.87
Race/ethnic background				
White	20%	24%	0%	
African American	31%	30%	38%	.001
Latino	41%	38%	56%	
Mixed/other	8%	8%	6%	
Education				
College graduate	33%	66%	16%	
High school graduate	42%	15%	22%	<.0001
Less than high school	25%	19%	63%	
Medicaid insurance	45%	39%	77%	.0001
Duration of asthma, years (mean \pm SD)	21 \pm 14	20 \pm 14	25 \pm 15	.06
Had prior hospitalizations for asthma	50%	48%	59%	.23
Used inhaled corticosteroids daily	78%	78%	75%	.68
Used inhaled β agonists daily	93%	93%	93%	.88
Used oral β agonists daily	6%	6%	3%	.46
Described access to care as difficult or very difficult	8%	8%	9%	.76

Table 2. Impact of Health Literacy on Outcomes with Sequential Addition of Covariates

Models*	AQLQ		SF-36 PCS		Treated in ED	
	Coefficient	P Value	Coefficient	P Value	Coefficient	P Value
1 Literacy [†]	0.66	.009	6.54	.0007	0.86	.04
2 Literacy	0.69	.005	6.69	.0005	0.93	.02
3 Asthma severity [‡]						
4 Literacy	0.61	.003	6.29	.0003	0.94	.03
5 Asthma severity						
6 Asthma self-efficacy [§]						
7 Literacy	0.52	.03	3.00	.11	1.11	.02
8 Asthma severity						
9 Asthma self-efficacy						
10 Age						
11 Education						
12 Literacy	.40	.07	2.23	.22	1.01	.04
13 Asthma severity						
14 Asthma self-efficacy						
15 Age						
16 Education						
17 Depressive symptoms [¶]						
18 Literacy	.20	.38	1.21	.53	.95	.07
19 Asthma severity						
20 Asthma self-efficacy						
21 Age						
22 Education						
23 Depressive symptoms						
24 Asthma knowledge						

*All analyses controlled for time in study.

[†]Measured with the Test of Functional Health Literacy in Adults.

[‡]Required daily oral β agonists.

[§]Measured with the Asthma Self-efficacy Scale.

[¶]Measured with the Geriatric Depression Scale.

^{||}Measured with the Check Your Asthma IQ Survey.

Scales: (possible score range) (higher is better status); AQLQ, Asthma Quality of Life Questionnaire (1 to 7); PCS, Physical Component Summary (0 to 100); ED, emergency department.

literacy and mental function (MCS scores) was not statistically significant ($P=.11$).

When health literacy was included in multivariable models for these outcomes along with other known significant independent variables, such as asthma severity, self-efficacy, knowledge, depressive symptoms, and demographics,⁸ health literacy no longer remained statistically significant. In addition, the relationship between health literacy and these other independent variables varied. For example, the correlation between health literacy and self-efficacy was low ($r=.05$, $P=.66$), but was stronger with depressive symptoms ($r=-.23$, $P=.004$) and knowledge ($r=.39$, $P<.0001$).

Thus, in the current analysis, we used a series of sequential models to document how the statistical association between health literacy and outcomes changed when these independent variables were included in the analysis. As shown in Table 2, when asthma severity, and then asthma self-efficacy, were added to the model for the AQLQ, there was little impact on the coefficients and P values for health literacy. However, when demographic characteristics, specifically age and education, and then depressive symptoms, were added to the model, the coefficients decreased, indicating attenuation of the effect of literacy. Finally, when asthma knowledge was added to the model, there was a marked change in the health literacy statistical values. Clinically, this may mean that one way in which less health literacy affects outcomes is by impeding the acquisition of asthma knowledge. Based on a more detailed analysis of health literacy and knowledge, we found that patients with less health

literacy had less knowledge about multiple topics. Table 3 shows the percent of patients who responded correctly to specific questions from the Check Your Asthma IQ survey according to health literacy group. Patients with less health literacy were less likely to consider asthma episodes potentially harmful, to know about warning signs, and to know about monitoring lung function. In addition, patients with less health literacy were less likely to know what a peak flow meter was (41% vs 64%, $P=.02$).

Similar sequential analyses were also carried out for

Table 3. Proportion of Patients Correctly Answering Selected Questions From the Check Your Asthma IQ survey

Question*	Literacy Level		P Value
	Adequate	Marginal/ Inadequate	
Asthma episodes may cause breathing problems, but these episodes are not really harmful or dangerous. (false)	89%	66%	.003
Asthma episodes usually occur suddenly without warning. (false)	32%	9%	.006
People with asthma have no way to monitor how well their lungs are functioning. (false)	74%	31%	<.0001
People with asthma should not exercise. (false)	95%	75%	.001

*Correct answer is in parentheses.

the physical function and emergency department outcomes (Table 2). Similar to the findings for the AQLQ, there was attenuation of the effect of health literacy on physical function as covariates were added to the model. Interestingly, there was less attenuation of health literacy on emergency department use as covariates were added. This implies that interactions between health literacy and other independent variables vary depending on the type of outcome.

DISCUSSION

In bivariate analyses, we found that less health literacy was associated with worse asthma-related quality of life, worse physical function, and more emergency department use over a period of 2 years. These relationships, however, were not maintained in multivariable analyses. Instead, our results suggest that health literacy continues to impact outcomes through its effects on other variables, particularly knowledge of asthma. This is the first longitudinal study we are aware of that assessed health literacy and its relationship with asthma outcomes and covariates.

It is not surprising that knowledge would be related to outcomes because knowledge is necessary for successful self-management, which is a critical element in current asthma treatment.¹⁹ Greater health literacy facilitates learning how to avoid triggers, manage medications, monitor symptoms, and use inhalers and peak flow meters. As such, adequate health literacy for asthma self-management means knowing asthma-related vocabulary and having specific reading and computational skills.²⁰

Two recent studies conducted in different populations and settings compared with our study also found strong associations between health literacy and knowledge in asthma patients. In one study, Medicare outpatients with inadequate health literacy were less likely to answer questions correctly about asthma precipitants, symptoms, medications, and what to do during a flare.⁶ Another study conducted with patients being treated for asthma in an emergency department or specialty clinic found that patients with lower reading levels were less likely to use an inhaler and to answer asthma questions correctly.⁷

In our study, it was interesting to find that health literacy was not associated with self-efficacy. In contrast, in the emergency department study described above, a relationship between health literacy and asthma self-efficacy was reported.⁷ However, in that study, self-efficacy was measured with only 2 questions, while in our study we used an 80-item comprehensive scale.¹⁴ One possible explanation for our findings is that self-efficacy may be primarily experience based, not instruction based. According to Bandura,²¹ self-efficacy is related to behaviors, such as having prior successes in similar situations and observing the successes of others. Thus, the ability to learn from experience, rather than to learn from formal instruction, may be the critical element in acquiring asthma self-efficacy.

In contrast to self-efficacy, in our study, we did find an association between less health literacy and more depressive symptoms. The relationship between depressive symptoms and asthma is complex, with each variable potentially exacerbating the other.²² Possible mechanisms for the interactions of mental health, depressive symptoms, and health literacy

have been proposed and include the role of overall health status.^{23,24}

We also found a strong association between health literacy and resource utilization. Specifically, patients with less health literacy were more likely to seek asthma care in the emergency department. Other studies also showed a link between health literacy and resource utilization. For example, emergency department patients and Medicare beneficiaries with inadequate health literacy were found to be more likely to be hospitalized over the next 2 years compared with patients with more health literacy.^{4,25}

This study has several limitations. First, it was conducted in a primary care urban practice and may not be generalizable to patients in other settings. In addition, patients in our sample were primarily young adults. Thus, our study did not measure the effects of health literacy in older patients, among whom illiteracy is more prevalent.²⁶ In addition, compared with the general asthma population, patients in our study may have acquired asthma knowledge simply by participating in our study and by answering our questionnaires. Second, our participants were patients with an established source of care and most had a long-term relationship with a physician. Thus, it is possible that physicians were aware of literacy limitations in certain patients, and already had modified their interactions to overcome this barrier.²⁷ Third, the small number of patients with marginal/inadequate health literacy and the unbalanced group size limited our ability to draw definitive conclusions. Finally, although the knowledge scale was administered in an interview format, it is possible that some patients may have responded incorrectly to some questions because they did not understand the questions (due to low health literacy) rather than because of less knowledge.

Our study showed that less health literacy is associated with poor asthma outcomes. In addition, this association is probably both direct, and indirect through effects on other independent variables, particularly patients' knowledge of asthma. To date, the role of health literacy has not been fully evaluated with respect to asthma. Our findings provide preliminary evidence that health literacy impacts knowledge of asthma and self-management. These, in turn, are critical determinants of asthma outcomes. Therefore, to improve asthma outcomes, researchers in health literacy should focus on ways to improve literacy skills that are required to learn, understand, and implement effective self-management.

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REFERENCES

1. **Parker RM, Ratzan SC, Lurie N.** Health literacy: a policy challenge for advancing high-quality health care. *Health Aff.* 2003;22:147-53.
2. **DeWalt DA, Berkman ND, Sheridan S, Lohr KN, Pignone MP.** Literacy and health outcomes: a systematic review of the literature. *J Gen Intern Med.* 2004;19:1228-39.
3. **Tomlinson LM.** Patient and practitioner literacy and women's health: a global view from the closing decade 1990-2000. *Ethn Dis.* 2003;13:248-58.
4. **Baker DW, Parker RM, Williams MV, Clark WS.** Health literacy and the risk of hospital admission. *J Gen Intern Med.* 1998;13:791-8.
5. **Schillinger D, Grumbach K, Piette J, et al.** Association of health literacy with diabetes outcomes. *JAMA.* 2002;288:475-82.

6. **Gazmararian JA, Williams MV, Peel J, Baker DW.** Health literacy and knowledge of chronic disease. *Patient Educ Counsel.* 2003;51:267-75.
7. **Williams MV, Baker DW, Honig EG, Lee TM, Nowlan A.** Inadequate literacy is a barrier to asthma knowledge and self-care. *Chest.* 1998;114:1008-15.
8. **Mancuso CA, Rincon M, McCulloch CE, Charlson ME.** Self-efficacy, depressive symptoms, and patients' expectations predict outcomes in asthma. *Med Care.* 2001;39:1326-38.
9. **Logorreta AP, Leung KM, Berkbigger D, Evans R, Liu X.** Outcomes of a population-based asthma management program: quality of life, absenteeism, and utilization. *Ann Allergy Asthma Immunol.* 2000;85:28-45.
10. **Parker RM, Baker DW, Williams MV, Nurss JR.** The Test of Functional Health Literacy in Adults: a new instrument for measuring patients' literacy skills. *J Gen Intern Med.* 1995;10:537-41.
11. **Juniper EF, Guyatt GH, Epstein RS, Ferrie PJ, Jaeschke R, Hiller TK.** Evaluation of impairment of health-related quality of life in asthma: development of a questionnaire for use in clinical trials. *Thorax.* 1992;47:76-83.
12. **Ware JE, Kosinski M, Bayliss MS, McHorney CA, Rogers WH, Raczek A.** Comparison of methods for scoring and statistical analysis of SF-36 health profile and summary measures: summary of results from the Medical Outcomes Study. *Med Care.* 1995;33:264-79.
13. **Tobin DL, Wigal JK, Winder JA, Holroyd KA, Creer TL.** The Asthma Self-efficacy Scale. *Ann Allergy.* 1987;59:273-7.
14. **Check Your Asthma IQ.** National Asthma Education Program. National Heart Lung and Blood Institute. *J Allergy Clin Immunol.* 1991;88:468-9.
15. **Yesavage JA, Brink TL.** Development and validation of a geriatric depression screening scale: a preliminary report. *Psychiatr Res.* 1983;17:37-49.
16. **Sheikh JI, Yesavage JA.** Geriatric Depression Scale (GDS): recent evidence and development of a shorter version. *Clin Gerontol.* 1986;5:165-73.
17. **Williams MV, Parker RM, Baker DW, et al.** Inadequate functional health literacy among patients at two public hospitals. *JAMA.* 1995;274:1677-82.
18. **SAS Institute.** SAS User's Guide. Version 5. Cary, NC: SAS Institute; 1985.
19. **Guidelines for the Diagnosis and Management of Asthma Expert Panel Report 2.** NIH Publication No. 97-4051. Bethesda, MD: National Asthma Education and Prevention Program; April 1997.
20. **Health Literacy: Report of the Council on Scientific Affairs.** American Medical Association. *JAMA.* 1999;281:552-7.
21. **Bandura A.** Social Learning Theory. Englewood Cliffs, NJ: Prentice-Hall; 1977.
22. **Alt HL.** Psychiatric aspects of asthma. *Chest.* 1992;101:415S-7S.
23. **Wolf M, Gazmararian JA, Baker DW.** Health literacy and functional health status among older adults. *Arch Intern Med.* 2005;165:1946-52.
24. **DeWalt DA, Pignone MP.** Reading is fundamental: the relationship between literacy and health. *Arch Intern Med.* 2005;165:1943-4.
25. **Baker DW, Gazmararian JA, Williams MV, et al.** Functional health literacy and the risk of hospital admission among Medicare managed care enrollees. *Am J Public Health.* 2002;92:1278-83.
26. **Gazmararian JA, Baker DW, Williams MV, et al.** Health literacy among Medicare enrollees in a managed care organization. *JAMA.* 1999;281:545-51.
27. **Mancuso CA, Rincon M.** Asthma patients' assessments of health care and medical decision making: the role of health literacy. *J Asthma.* 2006;43:41-4.